Title: What can trauma patients' experiences and perspectives tell us about the perceived quality of trauma care? A qualitative study set within the UK National Health Service

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Abstract

The global drive for improvements in the efficiency and quality of healthcare has led to the development of frameworks to assist in defining and measuring ‘good quality care’. However, such frameworks lack a systematic or meaningful definition of what ‘good quality care’ means from the patients’ perspective. The present research provides an in-depth analysis of patients’ experiences in a hospital setting from a quality of care perspective. Forty-five adults (aged 16-70) hospitalised in one of four UK NHS trusts following an unintentional injury were interviewed about their experiences of care. The findings show variability in perceived quality of care within the same hospital episode which cannot be meaningfully captured by existing frameworks. The context of trauma care (e.g. distressing nature of injury, patient vulnerability, expectations of hospitalisation and participants’ interaction with different service providers) defined the care experience and the value of being ‘cared for’. Participants identified some aspects of good and care which related to holistic, person-centred and personalised care beyond the medical needs. Participants discussed the value of being understood, staff thinking of their needs beyond hospitalisation, staff trying ‘their best’ despite constrains of current care, having their emotional needs recognised and addressed and staff competence.

Patients reported also poor quality of care and ‘not being cared for’ by specific staff groups which they expected to fulfil this role, rushed and unsympathetic care, lack of recognition for emotional impact of injury mapped onto existing quality frameworks e.g. safety, equity, accessibility and patient-centeredness as well as quality of interaction with providers, empathetic care which extended beyond medical needs, coordination of care, and the positivity of care delivery as important dimensions of quality care with implications for their recovery. The findings have implications for quality frameworks and theoretical definitions of quality of care; they demonstrate the importance of patient experience in addition to

clinical effectiveness and safety as an essential dimension of quality care. In terms of practice, the findings support the need to incorporate knowledge and training of injured adults' psychological needs, and the value of interaction with professionals as a patient defined dimension of the quality of care.

Keywords: experience of care, patient perspective, trauma, vulnerability, psychological needs

INTRODUCTION

The quality of care provided by health services remains an area of concern to policy-makers even in highly resourced countries like the UK[1]. This is due to variations within and between providers[2-3], mismatch between spending and care quality[4], costs associated with poor quality care and the economic impact of quality improvement[5].

Quality of care is variously defined and conceptualised within differing quality frameworks[3,4,6]. Key components across frameworks include: effectiveness (degree of achieving desired outcome), safety (avoidance or prevention of adverse outcomes), patient-centeredness or responsiveness (degree to which patients are at centre of care), accessibility (easiness of reach), equity (degree to which the system deals fairly with all patients and concerns), and efficiency (optimal use of available resources for maximum benefit)[3,4]. These components have been operationalised in practice, e.g. in the rating scale used by the UK Care Quality Commission[7] which rates hospital performance from 'outstanding' to 'inadequate'. The ratings is based on services' safety, efficacy, caring, responsiveness, leadership and fundamental standards including; person-centred care, dignity and respect, consent, safeguard from abuse, food and drink, premises and equipment, staffing and duty of candour. Such components need incorporating into a system focussing on patients' needs, who are informed, and in control over their care, whilst having their values and preferences respected[3]. Patient experience having been identified as important[1,8] and is associated with clinical effectiveness and safety[9]. However, much research into improving quality of healthcare[10-12] does not take account of patients' voices and perspectives[13-14]. Patients' perspectives can help understand some key quality of care components[15] and identify areas for improvement. To date, few qualitative studies of patients' experiences of trauma care have been published. One derives key components of high-quality trauma care,

which include clinical care, holistic care and information and communication among trauma patients within the Canadian health care system16]. Another, focusses on inpatient trauma care in Australia, finding patients perceived their inpatient care to be of high quality, despite communication problems and delays in surgical treatment[17]. Post-discharge care was often poorly coordinated with no consistent point of contact for care post-discharge. A further paper reports on experiences of care amongst trauma patients in the UK, some of whom had been admitted to hospital, but findings were not considered in relation to the quality of care provided[18]. Other papers have a narrower focus, concentrating on the quality of care provided around discharge from a trauma centre[19], information and communication needs[20-21] or the role of primary care post-discharge from hospital[22]. Our paper focusses on using patients' experiences and perspectives to explore the quality of care throughout the patient's stay in hospital following traumatic injury.

There are specific contextual factors related to traumatic injury which may impact on patients' perceived experiences of care. Traumatic injuries occur suddenly, can affect multiple parts of the body, impacting on physical, psychological, social, occupational and financial functioning and quality of life over the short or longer term[23-35]. Dealing with these impacts requires a complex process of appraisal and adaptation[36]. In addition, trauma patients typically experience care from multiple health care providers, which may include different hospitals, departments within hospitals and discharge destinations[22,25]. This paper explores patients' experiences and perspectives of the care they received following hospitalisation for traumatic injury within the UK National Health Service in relation to existing quality frameworks and identifies areas for quality improvement.

MATERIALS AND METHODS

We undertook a qualitative study, nested within Impact of Injury study (IOIS)[37]. The IOIS is a longitudinal multi-site study of the physical, psychological, social and economic impact of unintentional injuries among working aged adults (N=668: age 16-70 years) admitted to acute NHS hospitals in Nottingham, Leicester, Bristol and Guildford between June 2010 and June 2012. A stratified sampling frame was used for recruitment to the IOIS to ensure inclusion of a range of common and less common injuries. Patients aged under 16 or over 70 or who had sustained a head injury were excluded. IOIS participants who had experienced injuries 1-4, 5-8 or 9-12 months earlier, were invited to take part in a semi-structured in-depth interview in 2013-2014. The different timeframes were used to account for different services participants access at different times following their injury. The topic guide was developed from a previous research study, the UK Burden of Injury Study[38]. The guide included questions on life after injury, care experience and gaps in services (table 1). Interviews were audio-recorded, transcribed and analysed using inductive thematic analysis[39] using Nvivo 10 software. One researcher coded all participant data within broad categories using line by line coding and developed first and second level codes. Other categories were identified during this process and summary memos were written for each interview. Codes were then explored in more detail, using NVivo, and the transcripts revisited on a number of occasions, comparing and contrasting comments between participants and within individual transcripts to check consistency of meaning. A senior researcher on the team independently coded 20% of the interviews to check the validity of code and theme development. A broad thematic coding frame was agreed by researchers from all study centres and a service user following independent coding of a sample (10%) of interviews. Anonymised interview quotes are identified by participants' gender, age, injury, timing of interview post-injury and study centre.

Ethical approval

Ethical approval was provided by the Nottingham Research Ethics Committee 1 (number: 09/H0407/29).

RESULTS

Overall, 169 patients were invited to participate in the study, of which 72 agreed and 45 were interviewed. This is because a suitable time could not be arranged, or because we had already interviewed others with similar characteristics. The interviewees' characteristics are shown in table 2. Half (53%) the interviewees were female, 24% had experienced multiple injuries and the majority (58%) were injured during falls. The median age of interviewees was 52.5 years and 39 (87%) described their ethnicity as 'white UK'.

Most participants reported both positive and negative experiences of care, regardless of the hospital they had been admitted to. Most participants encountered multiple professionals and were cared for in a range of settings during what was often a lengthy process of recovery. Three main overarching themes were identified in the data; the specific context of care for trauma patients, positive experiences of care and negative experiences of care.

The specific context of trauma care

The context of trauma care is a lens through which patients' experiences of care should be viewed. For most participants 'care' was described in terms of the medical, nursing and other forms provided, but also the feeling that they were (or were not) being '*cared for'*. Being cared for was important, both as an individual and specifically as someone who had

experienced a sudden and unexpected event which was physically and emotionally traumatic, which could leave the individual physically dependent and emotionally vulnerable.

> *"There were quite a few tears and* [I was] *cross with my foot, cross with the fact that I'd broken it, just depressed because you're in hospital and also disbelief most of the time that I was where I was, you know sort of that "how did I get there?"* (Female/51/single/0-4/C4)

For participants it was important to feel cared for in a respectful way, considering their current state of vulnerability:

> *'The staff were absolutely brilliant …they really looked after me… I didn't eat for a whole week they were really trying to help me and they were really good…they still made me feel like a person … they made me go to the showers every day and they helped me if I needed help but they wanted me to do it myself …so rather than just treating me as a …because it is quite humiliating really when you can't do anything for yourself ….they really supported me and pushed me on too it did really …You know it has been really hard because you kind of feel like being a baby again help'(female/29/single/0-4/C3)*

Feelings of vulnerability were compounded by participants' inexperience of hospital care prior to their injury. They were often uncertain about what was expected of them as a patient

in that setting and, in those circumstances, what help they could or should expect and how their behaviour might impact on the care they received.

> *"you're in an unusual environment and you're not quite sure what you should ask and what not. Obviously, they've got lots of people to see, you don't want to hold them up all the time but you're trying to get the information that you're after.'* (male/37/single/9-12/C4)

Anxiety (about diagnosis, prognosis, how much to use the injured limb etc) and pain, were also important contributors to feeling vulnerable.

> *But the service they [nurses] offered was very good. Probably the caring as much as anything else. ... sort of keeping it fairly upbeat rather than allowing you to sit there and think what could have happened. ... just observations and keeping, not allowing me to get depressed or morose about it which it could quite easily have happened. ... It could easily have gone the other way.* (male/57/multiple/5-8/C1)

> *[going to the toilet] involved a huge amount of mental and physical effort because I had to, then, so I had to walk up and down stairs with crutches before they'd let me home, well I could barely stand, and I was completely spaced out with painkillers (female/51/single/5-8/C2)*

For patients, it was important that the service providers recognised these vulnerabilities when offering their care throughout the 12 months after injury.

Positive experiences of care

Participants described positive experiences of care that was holistic, patient-centred, personalised and catered beyond their direct medical needs. This included meeting practical needs like food, physical comfort and help with the toilet. Participants described feeling "cared for" when they felt treated "as a person" and where staff demonstrated understanding of what the participant had gone through. They also felt "cared for" when they were provided with personalised care, which they felt met their individual needs, or care that provided support, encouragement and reassurance. Staff who were positive while remaining professional helped participants to emotionally process what they had gone through and positivity was important at a time of distress. Participants highly valued professionals they thought gave them enough time or were '*doing their best*' or '*did their utmost'* despite being overworked and the pressures the health system was under.

> *"And they were very reassuring and supportive. And they sort of didn't make you run before you could walk. Yes, that was with a physio in the hospital, physio gym, and it was really, really good with exercises tailored to your particular injury …. I was really impressed with it actually. I think it was very personalised".*
> (female/54/single/9-12/C4)

"the paramedic was a bloke he was very good actually I really liked him and what I liked was that he gave me eye contact… and then there was this really nice student nurse who was did her utmost to try and treat people like human beings" (female/54/ single/5-8/C3)

'Cared for' participants describe how staff cared about their wellbeing even after they were no longer under their care.

"she was very positive she asked me questions about getting dressed and things she was mainly concerned with did I have anybody at home to help. I think if I hadn't, she would not have let me go." (female/70/single/0-4/C2)

"I got the impression she was the only one trying to deal with loads and loads of patients who wanted to go home but she didn't stint with her time she was very positive" (female/70/single/0-4/C2)

Participants perceived care positively also where they felt staff were competent and experienced. This provided them with comfort and confidence that their care would go well.

"Overall I mean they were excellent … it appeared to be something that was a common injury that they were familiar with and knew how to deal with it, it would be done properly, it would be done well and then I'd be off and, you know, into recovery quite quickly and so there's some comfort in knowing that certainly." (male/37/single/9-12/C4)

"It [physiotherapy] was from a very sound knowledge base. I felt very confident in the knowledge the physio had. And she explained to me the physiology of what was happening". (female/54/single/9-12/C4)

Negative experiences of care

Not feeling "cared for" was one of the most common negative experiences of care (around 1/3 of patients). This was more often attributed to failings by individual members of staff than to systematic pressures or processes such as understaffing or limited NHS resources. There was some understanding amongst participants that it was difficult to provide individualised care in particular settings – the most commonly mentioned being emergency departments – but there were also strong expectations that, irrespective of other pressures, some professional groups should be caring in attitude as well as practice. Unsurprisingly, all participants interviewed expected nursing staff to be caring' and failure to live up to this expectation was the most commonly mentioned negative experience of care.

"but I felt there was a big distinction between nurses and patients and patients were, I think to say they were objects is unfair, because they clearly weren't trying to treat us as objects, but the way it came across was you know, you are here under our care - it was like a prison." (female/54/single/5-8/C3)

Care that was perceived as unempathetic, inattentive or that felt rushed was perceived negatively and contributed to feelings of vulnerability and left some participants unsure about whether the care they were being provided was safe or not.

"One of the nurses said to me 'catch the train'. I was in no fit state to catch a train ....They wanted me to go home in a taxi which was absolutely impossible. When I did actually go home in an ambulance it took two medics to sort of strap me in a chair and carry me in. I don't know how a normal taxi driver was supposed to have done that."(female/63/multiple/0-4/C1)

Some participants felt that the emotional impact of the injury was not openly discussed or dealt with and that emotional support would have been helpful.

"after you've had like such a well like a traumatic incident I was just trying to rest, you know, just trying to regain me composure and you couldn't rest … Probably just after the accident it might have been useful, you know, to discuss why it happened to me, why me. (male/45/multiple/9-12/C1)

Most participants trusted that the health professionals caring for them were competent, but for some, that trust was eroded by poor communication.

"I was then told that to get to the right person, the best doctor, I could not be operated on until Thursday [patient had been admitted to hospital on Monday] because the best person to do it wasn't working until the Thursday, which I was pretty cross with but then I thought well ok if I am getting the best person I would rather wait and get the best person. And then suddenly on the Tuesday night they said to me you can't have anything to eat and I said why and they said because you are being

operated on in the morning and I said well hang on a minute I was told the best person does not work until Thursday, why am I now being palmed off with someone that isn't the best person? And they said oh no no no, this is the best person and I sort of said well make your mind up and I said I need to be re-assured now and they sent me I don't know who it was, the understudy to the consultant and somebody else to reassure me that I was definitely seeing a very very good surgeon and he actually was the best so erm I felt a bit better after that." (female/52/single/0-4/C4)

Problems with the coordination of care, compounded by poor communication between staff and patients about their care was another common negative experience, reported by nearly one third of participants. Examples included repeatedly cancelled operations, a lack of explanation or apology for deficiencies in care coordination, failure to prescribe pain relief and a medication error. Some participants felt they had to coordinate their own care and contact health professionals themselves or check that one health professional had received information from other health professionals.

"I went on the Wednesday evening and I didn't have the operation till Sunday. I was cancelled every day. I wasn't very happy you know because they [other patients] kept coming in after me and going down within three hours…. No I never got an apology. They just came and said about 7 o'clock at night you're cancelled, what do you want to eat? And it was usually a bowl of cornflakes, a quick cup of tea and then an hour later they say you're going down tomorrow so they'd take everything away from you, water as well". (female/69/multiple/5-8/C1)

"I was in eight days altogether until I actually said, you know, 'what am I doing here, why can't I go home' and it was then that they discovered when the doctor came, that nobody had actually prescribed any pain relief at all for all the time I'd been in… nobody had thought to give me any pain relief. … nobody seemed to know why I was there, I had to remind one member of staff to give me the injection, … when I asked how much longer I was going to be there, nobody seemed to know who I was under," (female/68/single/0-4/C1)

In an extreme example, one participant felt staff lacked the skills to adequately care for his injuries, leading him to discharge himself and self-refer to another hospital.

"unfortunately, people were getting a little bit confused about my injuries and I was getting concerned that no-one actually knew what was going on… I knew my previous injuries and what I had from this accident and even the doctors at the hospital were getting confused on what injuries were when and how they were done and etc., so I decided it was best for me to move on and I had a back specialist in [name of place] anyway, which I dealt with obviously when I broke my back before, so I knew I was going to be under him once I got back". (male/40/multiple/9-12/C1)

DISCUSSION

Main findings

Our study found both positive and negative experiences of care within all hospitals to which our participants were admitted. We found that patients' experiences and perspectives of

trauma care related to several domains of care quality frameworks. The majority of patient experiences, both positive and negative, related to patient-centred care. Whilst there are varying definitions of patient centred care, there is considerable consensus on its core principles [40] which emphasise: the patients centrality in the delivery and design of healthcare services, respect for patients' priorities and subjective experience, the collaborative nature of the therapeutic relationship, knowledge sharing and effective multi-disciplinary input and communication.' Important dimensions such as patients' rights, responsibilities and safety which are frequently omitted from these definitions are increasingly also acknowledged as key.

Trauma patients' experiences highlight the importance of similar principles of patient-centred care as defined by the Picker Institute[41] which make up the NHS Patient Experience Framework[42]. These include respect for patients' values, preferences and expressed needs, coordination of care, physical comfort, emotional support, information and education and continuity and transition. A much smaller number of experiences, both positive and negative, related to perceptions of staff competence and safety of the care being provided. It is clear from our research that patients' experiences provide insight into how to improve the quality of care provided. Our research also showed the importance of understanding the specific context of trauma care, and how the sudden nature of the traumatic event, physical dependence, physical and emotional vulnerability, unfamiliarity with and expectations of healthcare services may impact on patients' experiences.

Comparisons with previous research

Previous research has often used generic frameworks of quality of care with few studies considering patients' experiences during hospitalisation[22,25] or the context of illness.

Major stressful life events like illness and accidents can transform the way individuals see themselves and their future. For example, Field and colleagues[44], noted in their study of intensive care patients transferred to a general ward, that physical dependence increases perceptions of vulnerability. Serious illness (and we would argue, by extension, injury) is an emotionally complex situation in which even the most confident individuals may move between 'consumerist' and 'passive patient' roles or occupy both simultaneously[45]. This vulnerability combined with perceived poor care, contributed to further anxiety and worry amongst our participants.

Where research on patient experience exists, it supports the findings of this study such as the importance of staff professionalism, holistic care and communication[16,25,43], delays in care and poor coordination of care[17,22,43]. In our study, poor perceived staff professionalism was mostly related to poor communication which can be easily addressed and thus reduce patients concerns.

The significance of communication and information is well documented. Our findings are consistent with those of previous and current studies in trauma populations, including two from the impact of Injuries Study[22,25] and those from the RESTORE (Recovery after Serious Trauma—Outcomes, Resource use and patient Experiences) project in Australia[34]. Our study highlights the importance of effective communication between staff and patients and between healthcare providers particularly when multiple health professionals are providing care and at transition points such as hospital discharge like previous research[19-20,22,25]. Effective communication was characterised in one study as active discussion, clear language, listening and an empathetic manner, echoing our findings. Out study shows how the ability to achieve of failure to achieve these components of communication impacted on perceived quality of care at a vulnerable time for our patients. Although the present

research focused on experience of care during hospital, positive or negative experiences of care at an early stage could impact further experiences after leaving the hospital.

The major issue with holistically care related to poor recognition and the addressing of psychological and emotional needs. Given the value of the quality of interaction, health professionals need to build patient rapport/empathy at the outset post injury to recognise and help patients manage their psychological distress. The psychological impact of injuries as well as the negative impact of inconsistent care must be acknowledged and addressed by service providers and commissioners of services. This need was highlighted by the influential NHS Clinical Advisory Group (CAG) report (2010) 'Regional Networks for Major Trauma' [46] which after examining the evidence, guidance and research regarding trauma services delivery led to development of regional trauma networks and multi-speciality Major trauma centre hospitals. This report found psychological services were restricted to specific services and wider implementation was impeded by lack capacity; it proposed a stepped care approach to managing psychosocial problems following all major trauma [46]. Our findings suggest that these are still not universally implemented.

Strengths and limitations

This study interviewed a large sample of patients who had suffered a wide range of injuries. A multi-disciplinary team (nurses, physios, psychologists, GP, PPI) designed, conducted in four centres and analysed the study. Despite a sampling strategy aimed at recruiting a range of patients, it is possible those who responded were particularly satisfied or dissatisfied with the care they received. Two thirds of the participants were aged between 50 and 70. It is unknown whether the expectations of hospital care amongst the middle-aged are likely to be

different in some respects from other age groups. The interviews were conducted post-discharge and it is possible that later experiences of coping with injury and care[22,25] affected the appraisal of hospital care. On the other hand, it is possible that contact with other service providers following discharge provided comparators for the experience of in-patient care. The temporality of this influence could not be established in the present research.

A further limitation relates to the time of data collection which was completed in 2014. It is likely that changes have taken place on type of services provided. However, our research shows that it is the nature of hospitalisation and interaction with providers that makes a difference in the experience of care. These are unlikely to have changed in all services in the last 5 year. New research should investigate if there have been substantial changes since the CAG report and consider that patients' past knowledge and feelings might influence current experience of care.

Conclusions

Our study identified several components of care quality from patients' perspective during hospitalisation. The findings highlight the importance of the context of hospitalisation, as well as patients own views of what constitutes good and poor care. These include quality of interaction with professionals and the importance of addressing distress experienced during hospitalisation following their injury. Existing frameworks of quality of care need to be extended to include experiences and perspectives of patients themselves perceive as important, including the ones from the present study.

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